STUDY METHODS & DESIGN

Designing a Community Study of Moderately to Severely Disabled Older Women: The Women's Health and Aging Study

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PURPOSE: This paper reports on the design of a community-based study focusing on the effects of prevalent and incident disease and other modifying influences, on changes in functioning among moderately and severely disabled elderly women over a 3-year period [the Women's Health and Aging Study (WHAS)].

METHODS: An approach to conceptualizing and assessing disability which captured functional difficulty across a broad range of activities and tasks was developed, tested on existing national data, and used, in the form of a brief screening instrument, to identify moderately to severely disabled elderly women in a large community sample representative of women 65 and older. Women meeting study criteria were recruited for a baseline interview, a 3-hour in-home clinical exam, as well as follow-up interviews and physical performance tests at 6-month intervals for three years.

RESULTS: Prevalence of moderate to severe disability among the screened population proved similar to that expected from analysis of national data (about one-third). The screening interview response rate was 78%, and 71% of women eligible by disability criteria participated. Only women completing both the baseline interview and clinical exam were counted as respondents. Analysis of characteristics of participants and nonparticipants indicated no selection bias related to levels of disability. However, education, race, and age were associated with participation. Women with some college education, black women, and younger women were more likely to participate.

CONCLUSIONS: The approach used to identify and recruit moderately to severely disabled elderly women in the WHAS is both feasible and applicable to other community-based research where inclusion of elderly people with moderate to severe disability across several areas of functioning is an objective. Other aspects of study design, such as use of proxy respondents, will also affect recruitment of individuals with impaired functioning into epidemiologic studies. *Ann Epidemiol 1999;9:498–507.* © 1999 Elsevier Science Inc. All rights reserved.

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INTRODUCTION

Functional status and disability are key concepts in the field of aging. Maintaining functioning and preventing or reducing disability are of critical interest to clinicians who treat elderly people, policymakers who evaluate service needs related to disability in old age, and older people themselves. The Women's Health and Aging Study (WHAS) was undertaken to investigate changes in functional status in elderly women with moderate to severely impaired functioning. Several previous studies have been primarily concerned with transitions to disability (1, 2), and research is clarifying the role of specific diseases (3, 4, 5) and combinations of diseases (6) in disability. By focusing on a population with varying types and levels of impaired functioning, the

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Selected Abbreviations and Acronyms

WHAS = Women's Health and Aging Study
ADL = Activities of Daily Living
IADL = Instrumental Activities of Daily Living
SOA = National Health Interview Survey Supplement on Aging
MMSE = Mini-Mental State Examination

WHAS intends to map the effects of prevalent and incident disease and other modifying influences on changes in functioning over time (7). Women are of particular interest because they disproportionately survive into old age and develop physical disability.

The research focus of the WHAS presented challenges that are relevant for other studies that seek to define and enroll a community-based population with significant disability. First, disability had to be defined so as to capture varied types of functional limitations. Our approach was to investigate the prevalence of various limitations using a national dataset, and from this analysis develop a screening instrument to identify moderately to severely disabled women. Second, there was concern about the ability and willingness of women with significant health problems and functional limitations to participate in a research study involving multiple interviews and in-house clinical evaluation and testing. We report the experience with study recruitment of women identified as moderately to severely disabled. Study participants and eligible women who refused to participate are compared on functional status and other attributes. Characteristics of moderately to severely disabled elderly women drawn from national data and those identified through screening a community sample are also examined.

METHODS

Developing a Multidimensional Definition of Disability

Definitions of disability suggest a complex state that involves individuals, their environment, and multiple aspects of routine daily life. Descriptions of the disabled state include: limitations in performing social roles and tasks in relation to a socio-cultural and physical environment (8); limitations in relation to work, family, or independent living that arise from limitations in "performance of the human organism," (9); and difficulties experienced in doing activities in any domain of life due to a health or physical problem (10). The most commonly used measures of disability in studies of elderly people are limitations in the Activities of Daily Living (ADL) (e.g., bathing, dressing, eating, toileting) (11) and the Instrumental Activities of Daily Living (IADL) (12). ADLs have been described as those tasks "necessary for survival" (9), whereas IADLs represent more complex

tasks viewed as necessary to function independently in a community living environment (e.g., meal preparation, shopping for groceries or personal items, doing housework).

ADLs and IADLs have proven extremely useful in population-based studies of disability and its correlates, and for predicting service needs. However, they have drawbacks as a basis for identifying a study cohort if the objective is to achieve representation of heterogeneous manifestations of disability and varying levels of severity. Disability manifests itself in varied and complex ways and ADLs as well as IADLs primarily capture its expression in tasks. Other expressions of disability, in mobility for example, cannot be gleaned from these measures. In addition, both indicators have limitations as a basis for selecting individuals with varying levels of severity in functional difficulty.

The use of ADL tasks alone (typically bathing, dressing, eating, transferring, and toileting) identifies those at the extreme end of the disability spectrum (those who are most severely disabled). The use of IADL tasks alone, on the other hand, is broadly inclusive in an elderly population. For example, based on difficulty in one or more of six IADL tasks, two-thirds of women 85 and older are disabled (13). But unlike ADLs, where a relatively well-established hierarchy exists (e.g., difficulty eating is consistently the least common ADL limitation, followed by toileting), no hierarchy of severity has been established among IADL limitations in tasks, such as meal preparation or shopping. Developing a measure that reflects levels of severity in functional limitations based on both ADL and IADL also remains problematic, since a hierarchy among ADL and IADL items has not been clearly established. While some argue that a hierarchy between ADL and IADL items that reflects extent of disability and need for assistance can be established (14), others have found evidence against a hierarchical relationship (15).

One proposal for expanding the scope of functional assessment is that of Fried and coworkers (16). In a factor analysis of over 5000 community-dwelling people aged 65 and older, a set of items measuring difficulty in various types of activities and tasks were found to group into four domains of functioning: mobility and exercise tolerance, upper extremity function, complex tasks heavily dependent on cognition, and basic self-care tasks. The two task-related areas included items frequently found among ADL and IADL measures. The items that were correlated and designated as representing upper extremity function are not typically included in functional assessment based on ADL and IADL, however. Furthermore, mobility, which has been incorporated by some analysts into ADL measures (13) and by others into IADL (17), is viewed as a separate functional domain.

There are a number of approaches used to measure function and setting thresholds of disability. Some allow representation of individuals in multiple states of functioning (18, 19), whereas others, like the one used here, are based on categorical classification. This conceptualization has three

500 Kasper et al.
DESIGNING A COMMUNITY STUDY OF DISABLED OLDER WOMEN

AEP Vol. 9, No. 8
November 1999: 498–507

advantages as a framework for developing an approach needed to identify moderate to severely disabled elderly women. First, it provides a means of broadening the assessment of functioning beyond task performance. At the same time, some comparability with ADL/IADL assessment is maintained because the two task-related domains include items frequently used in ADL/IADL. Second, the variations in prevalence of difficulty across these domains, reported by Fried and coworkers (16), suggests the possibility of a hierarchy which can be used to distinguish gradations of severity among people with functional disability—36% of individuals reported difficulty in mobility/exercise tolerance, 18% in upper extremity function, 8% in complex tasks, and 3% in basic self-care. Third, the same analysis indicated that a relatively parsimonious set of items can be used to assess difficulty in these areas of functioning. In large-scale epidemiologic community studies, ADL and IADL assessment, typically, is based on fewer than 20 items (cf. 13, 17, 20). The framework and analysis by Fried and coworkers (16) offers the possibility of expanding the scope of functional assessment without increasing the number of questionnaire items.

Using National Data to Assess a Multidimensional Measure of Disability

Although a framework based on domains of functioning (mobility and upper extremity) and task performance (higher functioning and basic self-care) was promising as an approach to assessing disability, little was known about the cumulative prevalence or hierarchy of difficulty in these areas among elderly women. We used the National Health Interview Survey Supplement on Aging (SOA) (2), which provides data on a nationally representative sample of non-institutionalized, community-dwelling elderly adults, to investigate these issues. Among the many questions included in this survey were items like those associated with domains of functioning in Fried and coworkers (16). Seventeen individual items were used in this analysis: three items in the upper extremity functioning domain and four items in each of the others (see Table 1 for items in each domain). An indication of difficulty with functioning on any individual item within a domain was taken as an indication of disability in that domain.

Nationally, about 53% of all elderly women living in noninstitutional community settings reported difficulty in at least one of these four domains of functioning (Table 1). Women with difficulty in one or two domains primarily reported problems related to upper extremity or mobility functioning (about 90%). Two-thirds of women with difficulty in basic self-care were disabled in the other three domains as well (8.7% of the 13.1% with difficulty in basic self-care), and only 6% had difficulty in only two domains.

It was also apparent from these national data that preva-

TABLE 1. National data on functional status of elderly women overall and by age[a]

Number of domains with difficulty functioning[b]	Age			
	Total	65–74	75–84	85+
Total	100.0%	100.0%	100.0%	100.0%
(N)	(6854)	(4010)	(2267)	(577)
0 domains	46.9	55.2	38.8	19.4
1 domain				
Upper extremity (U)	4.2	4.9	3.6	2.2
Mobility/exercise tolerance (M)	15.5	14.6	17.6	12.9
Higher functioning tasks (H)	—	—	0.7	0.8
Basic self-care tasks (B)	—	—	—	—
2 domains				
U and M	11.6	11.7	11.7	10.4
M and H	2.8	1.9	3.3	7.2
M and B	0.8	0.7	1.0	0.7
Other combinations	—	—	—	0.5
3 domains				
U, M, and H	5.0	2.7	7.3	12.2
U, M, and B	2.1	1.9	2.3	2.3
U, H, and B	1.5	—	—	—
M, H, and B	—	0.9	1.5	5.7
4 domains	8.7	4.8	11.4	25.5

— Less than 0.05%.
Note: The distribution of number of domains with difficulty differed by age at p < 0.001.
[a] Data from 1984 National Health Interview Supplement on Aging for women 65 and older.
[b] 17-item battery used to assess difficulty in functioning within domains:
   Upper extremity (U):
      Raising arms up over head
      Using fingers to grasp or handle
      Lifting/carrying something as heavy as 10 lbs., e.g. bag of groceries
   Mobility/exercise tolerance (M):
      Walking 1/4 mile
      Walking up 10 steps without resting
      Getting in and out of bed or chairs
      Doing heavy housework
   Higher functioning (H):
      Using the telephone
      Doing light housework
      Preparing meals
      Shopping for personal items
   Basic self-care (B):
      Bathing or showering
      Dressing
      Eating
      Using the toilet.

lence of difficulty in upper extremity functioning, mobility/exercise tolerance, higher functioning tasks, and basic self-care tasks varied with age. Among elderly women aged 85 and over, about 80% were disabled in one or more of these four domains, in contrast to 45% of 65 to 74 year-olds. Numbers of functional domains affected varied with age as well, with a much higher percentage of very old women reporting difficulty in three or four domains (45%) than occurred at younger ages (10% of 65–74 year-olds; 22% of 75–84 year-olds). One-third of younger women, on the

TABLE 2. National data for elderly women on relationship of health status indicators to number of domains with difficulty functioning[a]

Health status indicators	Number of domains with difficulty functioning				
	0	1	2	3	4
Percent with:					
Hospital stay in prior year	10.7%	18.2%	25.0%	32.4%	44.4%
Bed days in prior 2 weeks	2.0%	5.4%	9.0%	13.3%	30.1%
Reporting fair or poor health	11.9%	31.6%	50.6%	62.2%	74.2%
Odds[b] of:					
Hospital stay in prior year	—	$1.85^{(1.53,2.25)}$	$2.78^{(2.32,3.33)}$	$4.00^{(3.21,4.97)}$	$6.66^{(5.33,8.32)}$
Bed days in prior 2 weeks	—	$2.80^{(2.00,3.89)}$	$4.86^{(3.35,7.05)}$	$7.54^{(5.02,11.26)}$	$21.08^{(15.49,28.69)}$
Reporting fair or poor health	—	$3.39^{(2.93,3.91)}$	$7.51^{(6.30,8.94)}$	$11.83^{(9.70,14.42)}$	$20.62^{(16.71,25.45)}$

[a] Data from 1984 National Health Interview Supplement on Aging for women 65 and older.
[b] Odds ratios with 0 domains as reference categories. Confidence intervals in parentheses.

other hand, reported difficulty functioning in only one or two domains with most indicating upper extremity and mobility/exercise tolerance difficulties.

The relationship of increasing age to disability is well-documented based on ADL and IADL measures (13, 21). These analyses indicated that when a broader range of functioning was considered this relationship still held, but very old women were disproportionately represented among those with difficulties in multiple domains, whereas younger women had functional difficulties that might not be captured by measures that focus only on ADL and IADL limitations.

Other recognized indicators of health status associated with ADL/IADL limitations (22, 23) were also examined to evaluate their relationship to disability when measured as difficulty in four domains of functioning. Table 2 shows that as number of domains with difficulty increased, percentages of elderly women with a hospital stay during the year, bed days in the prior two weeks, and who reported fair or poor as opposed to excellent or good health, also increased. Only 11% of women with no difficulty in any of the four domains reported a hospital stay in the previous year, for example, in contrast to 25% of those with difficulty in two domains and 44% of those with difficulty in all four. The odds of experiencing these adverse health states by number of domains with difficulty are also shown. Compared to women with no difficulty, the odds of reporting fair or poor health were 12 times greater for those with difficulty in three domains, and 21 times greater for those with difficulty in all four domains. Each increase in the number of domains with difficulty was also associated with a significant increase in the odds of a hospital stay in the prior year and bed days in the prior two weeks.

Implications of National Data Analysis for Assessment of Disability in a Community Population of Elderly Women

This analysis of national data suggested that by using a small set of items reflecting difficulty in four areas of functioning, variability across a broad spectrum of functioning could be captured. These data also indicated that one WHAS design objective—identifying the one-third most disabled elderly women—could be achieved by using a cut-point of difficulty in two or more domains of functioning. A second objective, including women with moderate as well as severe functional difficulties, also appeared feasible since about a third of those meeting criteria of difficulty in two or more domains had only upper extremity and mobility difficulties.

One other aspect of this analysis influenced the final study design. Because prevalence of difficulty in two or more domains of functioning varied by age, and equal representation of women in each of three age groups was desired given the research objectives, age-stratified random sampling was used to select the population to be screened on functional status.

RESULTS

Screening on Functional Status in a Community Sample of Elderly Women

The sampling frame consisted of all female Medicare enrollees age 65 or older in the geographic catchment area of the study (12 adjoining zip codes in Baltimore City and Baltimore County). Sample sizes were established for each of three age groups, 65 to 74, 75 to 84, and 85 and older, designed to yield at least 300 women meeting eligibility criteria in each group (24). These varied based on the proportion expected to meet disability criteria and the proportion expected to be ineligible due to nursing home residence or cognitive impairment. From 32,538 women, 6521 were sampled and 5316 were eligible for screening once those living in nursing homes and recently deceased were removed.

Table 3 indicates that a higher percentage of younger women agreed to the screening interview (81%) than did older women (78% and 73%, for ages 75–84 and 85 or older, respectively). This was not unexpected. In the National Health and Nutrition Examination Survey which conducts an interview in the home and a clinical examina-

502   Kasper et al.
DESIGNING A COMMUNITY STUDY OF DISABLED OLDER WOMEN

AEP Vol. 9, No. 8
November 1999: 498–507

tion in mobile examination centers, response rates decreased with increasing age (25).

Projections of prevalence of functional disability in two or more domains from analysis of the SOA were largely borne out while screening the WHAS community population of elderly women. Overall, about 34% of those who agreed to the screening interview were classified as disabled in two or more of four domains of functioning, based on answers to 17 items which asked about difficulty in specific activities and tasks (see Table 1; the final set of items used and the screening questionnaire also are available (26)).

As expected, there were differences in prevalence of moderate to severe disability according to age group in the community sample. Only 27% of women ages 65–74 met the criteria of difficulty in two or more domains, compared to 36% of 75–84 year-olds and 43% of women 85 or older. The prevalence of difficulty in two or more domains among younger women was similar to that from analysis of national data (25%). For the oldest women, however, the SOA indicated that a much higher percentage would be classified as disabled in two or more domains (65%) than was observed in the community screening. Two differences in study design, relating to eligibility criteria, may account for differing prevalence between the two studies of moderate to severe disability in the oldest age group. These are the exclusion in the WHAS of women who were unable to answer the screening interview questions about functional status by self-report, and of those who had Mini-Mental State Examination (MMSE) scores of less than 18. Use of proxy respondents in the SOA allowed such women to be represented.

Women who were unable to answer for themselves questions on functional status were ineligible for the WHAS. This was necessary to avoid bias associated with self-report of functional status for some women and proxy report for others. Proxy respondents were accepted in later interviews as the study progressed when subjects were too ill or incapac-

itated to participate or had entered nursing homes. The WHAS screening interview was conducted in person in the subject's home. In some instances, after a few questions the inability of the subject to participate was clear; in others, a family member or other caregiver intervened and told the interviewer the subject was not capable of responding competently (this was often attributed to cognitive problems but whenever possible interviews were completed so that cognitive status could be determined based on MMSE). Some women also proved too ill or frail to complete the interview on their own.

Elderly women with MMSE scores below 18 (generally used as the cut-point for severe cognitive impairment and the most specific cut-point for dementia) (27) also were ineligible for the WHAS for both theoretical and practical reasons. Many of the primary research questions were inapplicable to women with severe cognitive impairment. In addition, there was concern about the ability of such women to participate in the lengthy clinical examination that was integral to the study. Of those agreeing to the WHAS screening interview, a much higher percentage of women 85 and older (31%) were ineligible based on these two exclusion criteria than were younger women (3% of 65–74 year-olds and 9% of 75–84 year-olds) (Table 3). Since neither criteria precluded participation in the SOA if a proxy respondent could respond for the subject, this could account for a higher prevalence of moderate to severe disability among the oldest age group in the national survey relative to the WHAS.

Study Participation and Refusal among Moderately to Severely Disabled Women

Among women invited to participate in the WHAS, the response rate at this second stage was 71% overall, ranging from 77% for women 65–74 years of age to 65% for those

TABLE 3. Screening results for functional assessment in 4 domains and study participants among moderately to severely disabled women (Women's Health and Aging Study)

Study eligibility and participation	Age group			
	65–74	75–84	85+	Overall
Screening interview sample	2331	1532	1444	5307
% (N) screened	81% (1888)	78% (1195)	73% (1054)	78% (4137)
Screening results				
Not eligible: MMSE score < 18 or inability to complete screening interview[a]	3%	9%	31%	12%
Not eligible: functional difficulty in fewer than 2 domains	69%	54%	26%	54%
Eligible: functional difficulty in 2 or more domains (moderately to severely disabled)	27%	36%	43%	34%
Eligible sample				
% (N) participating	77% (398)	71% (306)	65% (298)	71% (1002)

[a] Inability to complete the screener was often attributed by the interviewer or by family members to cognitive problems. To be eligible, subjects were required to complete 20-minute screening interview by self-report.

TABLE 4. Odds of study participation among elderly women with difficulty functioning in 2 or more domains[a] (Women's Health and Aging Study)

	Odds ratio	95% CI
Age[b]		
75–84	0.73[c]	(0.54, 0.99)
85+	0.59[d]	(0.43, 0.80)
No. domains with difficulty functioning[e]		
3	0.93	(0.69, 1.26)
4	1.10	(0.82, 1.46)
Perceived health status (fair/poor = 1)	1.02	(0.80, 1.30)
Race (Black = 1)	1.51[c]	(1.13, 2.02)
Education (grades completed)[f]:		
9 to 11	0.96	(0.70, 1.33)
12	0.88	(0.64, 1.22)
13 or more	1.56[c]	(1.09, 2.24)
Household size[g]:		
2	1.08	(0.82, 1.41)
3	1.25	(0.83, 1.90)
4 or more	1.09	(0.67, 1.78)

[a] Based on 1409 women who were eligible for WHAS, see Table 3. Data are unweighted.
[b] Reference category = 65 to 74.
[c] $p < 0.05$.
[d] $p < 0.001$.
[e] Reference category = 2 domains.
[f] Reference category = 8 or fewer grades completed.
[g] Reference category = one person household.

85 or older (Table 3). The study targeted a group of women many of whom were quite ill. Prevalence of self-reported chronic conditions among these moderately to severely disabled women was high. In the screening interview, 41% reported a heart attack or angina and 15% a stroke, for example, compared to 16% and 4% respectively among women not moderately to severely disabled (28). Approximately 7% of subjects died during the first year following the baseline interview. The WHAS also made substantial demands on the time and energy of study participants. Subjects were asked to participate in a lengthy baseline interview which would be repeated at six month intervals over three years, and to undergo a two to three hour clinical examination in their home two weeks after the initial interview (29).

Although the key objectives of the sample design were realized—recruitment of a large age-stratified cohort of elderly women with moderate to severe disability—and response rates were acceptable, there was concern about possible differential response by severity of disability. Because information was obtained in the screening interview on nonrespondents eligible for the WHAS, the opportunity existed to investigate differences on functional status and other characteristics between study participants and those who were eligible but refused to participate.

Table 4 shows that the odds of participating among eligible women did not differ according to the number of do-

mains in which difficulty was reported; more severely disabled women (difficulty in three and four domains) were no less likely to participate than moderately disabled women controlling for other factors. Nor was perceived health status (fair/poor vs. excellent/very good/good) a factor in study participation. There were differences by age, race, and education, however. Among eligible women the odds of participating in the study were about 40% less for those 85 or older, and 25% less for those 75–84, compared to 65–74 year-olds. Black women were one and a half times more likely to participate than white women. Women with 13 or more years of education also were one and a half times more likely to participate than women with fewer than eight years of education.

Household size was not related to study participation. There had been concern that family members might discourage participation in an effort to shield women with serious health problems from a potentially demanding or strenuous activity. The presence of others in the household appeared to have had no effect on the decision to participate among eligible women.

As reported earlier, response rates for study participation were relatively high (above 70% overall and in two of three age groups), which reduces the threat of selection bias due to nonresponse (30). However, some characteristics (age, education, race) were related to study participation. Explanations for these relationships cannot be derived from available data, but several factors should be considered. A small financial incentive ($15) was offered in connection with the clinical examination, and given at the first interview to women who agreed to participate. Studies have shown that even small payments can influence study response rates (31). The clinical examination itself may have been a deterrent for some women, but others may have seen it as a benefit. Results were forwarded to personal physicians with the subject's permission, and reported to the women themselves. Other intangibles, such as interviewer expertise, attitudes toward the sponsoring institutions (a federal agency and a major academic medical institution), interest in the study's subject matter (health and illness in elderly women) and views about the value of research, also may have influenced the decision to participate.

Comparison of a National Sample with a Community Sample of Elderly Community-Dwelling Women

Empirical analysis of national data played a central role in the research design of this community-based study of elderly women with moderate to severe disability. Therefore, following completion of study recruitment, we compared the final WHAS study sample against the national data. Table 5 shows overall, and within each age group, the distribution within each population of domains in which there was difficulty functioning. In the community sample, women

504   Kasper et al.
DESIGNING A COMMUNITY STUDY OF DISABLED OLDER WOMEN

AEP Vol. 9, No. 8
November 1999: 498–507

TABLE 5. Number of domains in which difficulty functioning was indicated: National data[a] and a Community sample (WHAS)[b]

| Elderly women | Number of domains with difficulty functioning | | | | |
	0	1	2	3	4
	(Percent distribution)				
Total					
National data	46.9	20.4	15.4	8.6	8.7
Community sample	44.6	20.3	13.6	9.7	11.9[c]
65–74					
National data	55.2	20.0	14.4	5.5	4.8
Community sample	51.8	19.9	12.8	7.4[c]	8.1[c,d]
75–84					
National data	38.8	22.3	16.3	11.2	11.4
Community sample	38.2	21.7	14.1	12.2	13.8[c]
85+					
National data	19.4	16.1	18.8	20.2	25.5
Community sample	22.0	16.7	17.3	14.3	29.7

[a] Estimates based on weighted data for women 65 or older from the 1984 National Health Interview Survey Supplement on Aging. Domains were constructed using the same items as in the WHAS. The population excludes nursing home residents.
[b] Estimates based on weighted data for 3635 self-respondents to Women's Health and Aging Study screening interview. The population excludes those with MMSE < 18 or unable to complete screener; see Table 3.
[c] Significantly different from national estimate using a 2-tailed Z-test at $p < 0.05$.
[d] Estimates are significantly different only for this cell if $p < 0.03$ is used to maintain a constant 0.05 probability of rejecting the null hypothesis when making multiple comparisons.

TABLE 6. Demographic characteristics and self-reported health problems of moderately to severely disabled elderly women: Comparison of national data[a] and a Community sample (WHAS)[b]

Demographic characteristics and health conditions	National data	Community sample
Demographics		
Race		
White	87.6	73.6
Black	12.4	26.4
Education		
< 8 grades	24.8	24.7
8 grades	19.1	16.1
9–11 grades	18.2	23.5
High school graduate	24.5	19.1
College or beyond	13.3	16.6
Household size		
1	46.6	46.4
2	36.1	34.0
3	9.3	11.3
4+	7.9	8.7
Health conditions		
# Chronic conditions[c]		
0	6.2	6.0
1	23.6	17.3
2	35.0	26.2
3	21.9	25.7
4	9.0	15.5
5+	4.2	9.4
Vision problems[d]	54.3	79.6
Hearing problems[d]	46.6	27.1

[a] Estimates based on weighted data for women 65 or older from the 1984 National Health Interview Study Supplement on Aging. Domains were constructed using the same item as in the WHAS. The population excludes nursing home residents.
[b] Estimates based on weighted data for 3635 self-respondents to Women's Health and Aging Study screening interview, excludes those with MMSE < 18 or unable to complete screener (see Table 3).
[c] The following conditions were included: 1) national data—angina, coronary heart disease, MI or heart attack, hypertension, diabetes, arthritis, stroke, cancer, and broken hip; and 2) community sample—angina, congestive heart disease, MI or heart attack, high blood pressure, diabetes, arthritis, stroke, cancer, and broken or fractured hip.
[d] The questions on vision and hearing were substantially different. The SOA asked whether subject "had trouble with vision (hearing)" and the estimate reflects responses of "a little" or "a lot." The WHAS asked "has a doctor ever told you that you had vision (hearing) problems?"

with no difficulty in any domain or difficulty in only one (who did not meet criteria for study eligibility), accounted for 65% of all women screened. National data indicated a similar percentage (67%) of such women.

Comparing percentages between the community and national populations within age groups also shows few differences between estimates. Based on tests of differences in proportions (2-tailed Z-tests using percentages and standard errors generated so as to reflect the appropriate variances for each sample design), comparisons of national and community estimates reached significance in only three cells (for 65–74 year-olds with three and four domains of difficulty, and 75–84 year-olds with four domains of difficulty). Since multiple comparisons were made, if the p-value was adjusted to guard against a higher probability of rejecting the null hypothesis of no difference between the estimates, national and community estimates differed significantly for only one cell (women ages 65–74 with difficulty in four domains).

Table 6 compares other characteristics of moderately to severely disabled elderly women defined by functional difficulty in two or more domains using national data and community data. Given the urban area represented by the WHAS sample, the higher proportion of black women is not surprising, 26% versus 12% nationally. Women of Hispanic or Asian ethnicity were largely absent (less than 1%

of women screened indicated their race was other than white or black, or they were of Hispanic origin), also a reflection of the demography of the city where the WHAS was conducted. The educational distribution differed significantly due to a lower percentage of high school graduates in the community sample, compared to national data, and correspondingly higher percentages with 9–11 grades completed and with college or beyond. However, in both data sets about one-quarter of moderately to severely disabled women had fewer than eight grades of education. There were no differences in household size between the national

level and the community population. In both, the percentage of elderly women living alone was quite high among those with difficulty in two to four domains of functioning, about 47%. A little over one-third resided in two person households.

Questions on various chronic conditions and health problems were asked as part of the SOA interview and in the WHAS screening interview. In both, only 6% of women with difficulty functioning in two to four domains had no chronic conditions. The proportion reporting one or two chronic conditions was 58% among women nationally, however, but only 43% of the community population. Conversely, only 13% of these moderately to severely disabled women were reported to have four or more chronic conditions nationally, compared to 25% of the WHAS population. One possible explanation is differences in the way conditions were described in the two interviews; for example, hypertension was asked about in one (WHAS) and high blood pressure in the other (SOA). As noted earlier, the use of proxy respondents in the national survey, but not in the community study screening interview, may also have resulted in differences in reporting disease prevalence. In general, however, underreporting has been documented for chronic diseases regardless of respondent (32, 33). One purpose of the clinical examination (29) and record surveillance components of the WHAS design, was to provide clinical evidence for disease prevalence.

There are large differences in prevalence between the WHAS and SOA data in vision and hearing problems within this moderately to severely disabled population. In this instance, the questions asked in the two interviews were quite different. In the national interview respondents were asked in separate questions whether they "had trouble with vision (wearing glasses or contact lenses)" or "hearing (with your hearing aid)." The community screening interview asked "whether a doctor has ever told you that you had vision or hearing problems." Among moderately to severely disabled women in the community sample, 80% indicated a doctor had said they had vision problems. The percentage of such women who reported trouble with vision in the national survey was 54%. It seems plausible that a larger percentage would report they have been told they had vision problems by a doctor, but a lower percentage would report they experience vision problems when using their glasses or contacts. For hearing, however, the reverse occurred. In the national survey, 47% of women with difficulty in two or more domains were reported to have trouble with hearing, but in the WHAS only 27% reported a doctor had said they had hearing problems.

Whether individuals have been diagnosed by a physician and whether they experience difficulty with hearing or vision, including when using aids meant to correct these problems, evoke different responses as these two surveys illustrate. On the whole, however, aside from expected differences such as

race and ethnic composition, a similar picture of the characteristics of moderately to severely disabled elderly women emerges whether national data or data from this urban community sample are used to describe this population.

DISCUSSION

The Women's Health and Aging Study presented several challenges in study design because the intended study population was a subset of elderly women with moderate to severe disability. The proposed design largely succeeded. An approach to conceptualizing and assessing disability which captured functional difficulty across a broad range of activities and tasks was developed, tested on existing national data, and implemented in the form of a brief screening instrument. A large random sample of elderly women stratified according to age group was screened. Women identified as moderately to severely disabled were recruited for the study (78% response rate). Over 70% of these women agreed to participate despite their health problems and impaired functioning. The prevalence of moderate to severe disability among the study sample proved similar to that found in analysis of national data. The analysis of factors influencing study participation and nonresponse indicated no selection bias related to levels of severity of disability.

These results suggest that the approach used to identify and recruit moderately to severely disabled elderly women in the WHAS, is both feasible and applicable to other community-based research where inclusion of elderly disabled people is an objective. There are two other aspects of study design that this experience indicates will affect recruitment into epidemiologic studies of people with significant functional difficulties. One is whether functional status is based on self-report only or proxy respondents are accepted. The WHAS required self-report in the screening interview. This questionnaire consisted of the 17 items on functioning used to distinguish women with moderate to severe disability from others, a limited number of demographic and health characteristics (e.g., prevalence of major chronic conditions, perceived health status), and the MMSE. Among women 85 and older, a much higher percentage were unable to meet the self-report requirement. Many large epidemiological studies allow proxy respondents for people who are severely disabled, particularly if few contacts are involved (e.g., one interview). In the National Long-Term Care Survey, for example, which targeted ADL and IADL-disabled elderly people for interview, the response rate to the survey exceeded 90%. However, for two-thirds of the ADL-disabled subjects age 85 or older, interviews were conducted with proxy respondents (35).

There is disagreement about the validity of proxy data on health and functioning relative to self-report, with evidence for both agreement (36) and substantial differences

506   Kasper et al.
DESIGNING A COMMUNITY STUDY OF DISABLED OLDER WOMEN

AEP Vol. 9, No. 8
November 1999: 498–507

between the two (37). Studies of people who are very disabled, regardless of age, must weigh the relative importance of high response rates, which can be raised substantially through use of proxies, against the value of self-reported data on health and functioning. In the WHAS, self-report in the initial screening interview was viewed as necessary for two reasons: 1) uncertainty about how proxy report of functional status might differ from self-report, and concerns about bias related to self-report for some subjects and proxy-report for others; and 2) the need to administer a test of cognitive functioning (the MMSE) to subjects to rule out the severely cognitively impaired.

Another aspect of study recruitment of interest is that very old age presents a barrier to study participation. Women age 85 and older were both less likely to agree to answer the questions for the screening interview and less likely to agree to study participation when eligible. Because of the age-stratified sample design, differences in response rate by age can be observed in the WHAS. The overall screening response rate was similar to that obtained in other large epidemiologic studies, only slightly lower, for example, than for the Established Populations for Epidemiologic Studies of the Elderly (1). Further investigation of the reasons for greater nonresponse at older ages, which may involve multiple factors ranging from attitudes to impediments such as hearing difficulties, is warranted, especially as research interest in the oldest old continues to grow.

The WHAS was intended to investigate change in functioning and important modifiers of change in a group of women with significant functional disability. Identifying and recruiting a study population that met the research objectives presented several challenges, both conceptually and in implementation. The approach used in the WHAS proved successful in yielding a study population of the desired size and heterogeneity, and provides an alternative to using ADLs and IADLs as a means of classifying and assessing physical disability. Many aspects of this approach are applicable to other studies of elderly ill and disabled people in the community, a group of increasing interest from both an epidemiological and health policy perspective.

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AEP Vol. 9, No. 8
November 1999: 498–507

Kasper et al.
DESIGNING A COMMUNITY STUDY OF DISABLED OLDER WOMEN

507

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